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## House of Representatives

### LIFESPAN RESPITE CARE ACT OF 2006

Mr. DEAL of Georgia. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 3248) to amend the Public Health Service Act to establish a program to assist family caregivers in ac-

cessing affordable and high-quality respite care, and for other purposes, as amended.

The Clerk read as follows:

H.R. 3248

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

#### SECTION 1. SHORT TITLE.

This Act may be cited as the "Lifespan Respite Care Act of 2006".

#### SEC. 2. LIFESPAN RESPITE CARE.

The Public Health Service Act (42 U.S.C. 201 et seq.) is amended by adding at the end the following:

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TRENT LOTT, *Chairman*.

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TRENT LOTT, *Chairman*.

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**"TITLE XXIX—LIFESPAN RESPITE CARE****"SEC. 2901. DEFINITIONS.**

"In this title:

"(1) **ADULT WITH A SPECIAL NEED.**—The term 'adult with a special need' means a person 18 years of age or older who requires care or supervision to—

"(A) meet the person's basic needs;

"(B) prevent physical self-injury or injury to others; or

"(C) avoid placement in an institutional facility.

"(2) **AGING AND DISABILITY RESOURCE CENTER.**—The term 'aging and disability resource center' means an entity administering a program established by the State, as part of the State's system of long-term care, to provide a coordinated system for providing—

"(A) comprehensive information on available public and private long-term care programs, options, and resources;

"(B) personal counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances; and

"(C) consumer access to the range of publicly supported long-term care programs for which consumers may be eligible, by serving as a convenient point of entry for such programs.

"(3) **CHILD WITH A SPECIAL NEED.**—The term 'child with a special need' means an individual less than 18 years of age who requires care or supervision beyond that required of children generally to—

"(A) meet the child's basic needs; or

"(B) prevent physical injury, self-injury, or injury to others.

"(4) **ELIGIBLE STATE AGENCY.**—The term 'eligible State agency' means a State agency that—

"(A) administers the State's program under the Older Americans Act of 1965, administers the State's program under title XIX of the Social Security Act, or is designated by the Governor of such State to administer the State's programs under this title;

"(B) is an aging and disability resource center;

"(C) works in collaboration with a public or private nonprofit statewide respite care coalition or organization; and

"(D) demonstrates—

"(i) an ability to work with other State and community-based agencies;

"(ii) an understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

"(iii) the capacity to ensure meaningful involvement of family members, family caregivers, and care recipients.

"(5) **FAMILY CAREGIVER.**—The term 'family caregiver' means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.

"(6) **LIFESPAN RESPITE CARE.**—The term 'lifespan respite care' means a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.

"(7) **RESPITE CARE.**—The term 'respite care' means planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

"(8) **STATE.**—The term 'State' means any of the several States, the District of Columbia, the Virgin Islands of the United States, the Commonwealth of Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

**"SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.**

"(a) **PURPOSES.**—The purposes of this section are—

"(1) to expand and enhance respite care services to family caregivers;

"(2) to improve the statewide dissemination and coordination of respite care; and

"(3) to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

"(b) **AUTHORIZATION.**—Subject to subsection (e), the Secretary is authorized to award grants or cooperative agreements for the purposes described in subsection (a) to eligible State agencies for which an application is submitted pursuant to subsection (d).

"(c) **FEDERAL LIFESPAN APPROACH.**—In carrying out this section, the Secretary shall work in cooperation with the National Family Caregiver Support Program of the Administration on Aging and other respite care programs within the Department of Health and Human Services to ensure coordination of respite care services for family caregivers of children and adults with special needs.

"(d) **APPLICATION.**—

"(1) **SUBMISSION.**—Each Governor desiring the eligible State agency of his or her State to receive a grant or cooperative agreement under this section shall submit an application on behalf of such agency to the Secretary at such time, in such manner, and containing such information as the Secretary shall require.

"(2) **CONTENTS.**—Each application submitted under this section shall include—

"(A) a description of the eligible State agency's—

"(i) ability to work with other State and community-based agencies;

"(ii) understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

"(iii) capacity to ensure meaningful involvement of family members, family caregivers, and care recipients;

"(B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite care workers and volunteers will be recruited and trained, a description of—

"(i) the population of family caregivers;

"(ii) the extent and nature of the respite care needs of that population;

"(iii) existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;

"(iv) existing methods or systems to coordinate respite care information and services to the population at the State and local level and extent of unmet need;

"(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

"(vi) a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on aging;

"(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of the proposed respite care activities;

"(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contributions, other

forms of reimbursements, personnel, and facilities;

"(ix) respite care services available to family caregivers in the eligible State agency's State or locality, including unmet needs and how the eligible State agency's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs;

"(x) the criteria used to identify family caregivers eligible for respite care services;

"(xi) how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver; and

"(xii) the results expected from proposed respite care activities and the procedures to be used for evaluating those results;

"(C) assurances that, where appropriate, the eligible State agency will have a system for maintaining the confidentiality of care recipient and family caregiver records; and

"(D) a memorandum of agreement regarding the joint responsibility for the eligible State agency's lifespan respite program between—

"(i) the eligible State agency; and

"(ii) a public or private nonprofit statewide respite coalition or organization.

"(e) **PRIORITY; CONSIDERATIONS.**—When awarding grants or cooperative agreements under this section, the Secretary shall—

"(1) give priority to eligible State agencies that the Secretary determines show the greatest likelihood of implementing or enhancing lifespan respite care statewide; and

"(2) give consideration to eligible State agencies that are building or enhancing the capacity of their long-term care systems to respond to the comprehensive needs, including respite care needs, of their residents.

"(f) **USE OF GRANT OR COOPERATIVE AGREEMENT FUNDS.**—

"(1) **IN GENERAL.**—

"(A) **REQUIRED USES OF FUNDS.**—Each eligible State agency awarded a grant or cooperative agreement under this section shall use all or part of the funds—

"(i) to develop or enhance lifespan respite care at the State and local levels;

"(ii) to provide respite care services for family caregivers caring for children or adults;

"(iii) to train and recruit respite care workers and volunteers;

"(iv) to provide information to caregivers about available respite and support services; and

"(v) to assist caregivers in gaining access to such services.

"(B) **OPTIONAL USES OF FUNDS.**—Each eligible State agency awarded a grant or cooperative agreement under this section may use part of the funds for—

"(i) training programs for family caregivers to assist such family caregivers in making informed decisions about respite care services;

"(ii) other services essential to the provision of respite care as the Secretary may specify; or

"(iii) training and education for new caregivers.

"(2) **SUBCONTRACTS.**—Each eligible State agency awarded a grant or cooperative agreement under this section may carry out the activities described in paragraph (1) directly or by grant to, or contract with, public or private entities.

"(3) **MATCHING FUNDS.**—

"(A) **IN GENERAL.**—With respect to the costs of the activities to be carried out under paragraph (1), a condition for the receipt of

a grant or cooperative agreement under this section is that the eligible State agency agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

“(B) DETERMINATION OF AMOUNT CONTRIBUTED.—Non-Federal contributions required by subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

“(g) TERM OF GRANTS OR COOPERATIVE AGREEMENTS.—

“(1) IN GENERAL.—The Secretary shall award grants or cooperative agreements under this section for terms that do not exceed 5 years.

“(2) RENEWAL.—The Secretary may renew a grant or cooperative agreement under this section at the end of the term of the grant or cooperative agreement determined under paragraph (1).

“(h) MAINTENANCE OF EFFORT.—Funds made available under this section shall be used to supplement and not supplant other Federal, State, and local funds available for respite care services.

**“SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CENTER.**

“(a) ESTABLISHMENT.—The Secretary may award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the ‘center’).

“(b) PURPOSES OF THE CENTER.—The center shall—

“(1) maintain a national database on lifespan respite care;

“(2) provide training and technical assistance to State, community, and nonprofit respite care programs; and

“(3) provide information, referral, and educational programs to the public on lifespan respite care.

**“SEC. 2904. REPORT.**

“Not later than January 1, 2009, the Secretary shall report to the Congress on the activities undertaken under this title. Such report shall evaluate—

“(1) the number of States that have lifespan respite care programs;

“(2) the demographics of the caregivers receiving respite care services through grants or cooperative agreements under this title; and

“(3) the effectiveness of entities receiving grants or cooperative agreements under this title.

**“SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.**

“There are authorized to be appropriated to carry out this title—

“(1) \$30,000,000 for fiscal year 2007;

“(2) \$40,000,000 for fiscal year 2008;

“(3) \$53,330,000 for fiscal year 2009;

“(4) \$71,110,000 for fiscal year 2010; and

“(5) \$94,810,000 for fiscal year 2011.”.

**SEC. 3. GAO REPORT ON LIFESPAN RESPITE CARE PROGRAMS.**

Not later than January 1, 2011, the Comptroller General of the United States shall conduct an evaluation and submit a report to the Congress on the effectiveness of lifespan respite programs, including an analysis of cost benefits and improved efficiency in service delivery.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from Georgia (Mr. DEAL) and the gentleman

from New Jersey (Mr. PALLONE) each will control 20 minutes.

The Chair recognizes the gentleman from Georgia.

**GENERAL LEAVE**

Mr. DEAL of Georgia. Mr. Speaker, I would ask that all Members have 5 legislative days within which to revise and extend their remarks and insert extraneous material on the bill.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from Georgia?

There was no objection.

Mr. DEAL of Georgia. I yield myself as much time as I may consume.

Mr. Speaker, I rise today in strong support of H.R. 3248, the Lifespan Respite Care Act of 2006. This legislation is an important first step in offering help to the estimated 25 million Americans currently caring for a sick, aged or disabled loved one at home. Whether it is an aged father or mother, a spouse who has suffered a work-related injury, or a child with a special need, almost all of us have either taken care of or know someone who is taking care of a loved one at home.

As an experienced caregiver for my mother and both of my wife's parents, I am personally aware of the benefits of at-home care. But I am also acutely aware that there are financial, emotional and physical burdens for the family caregiver that can sometimes be overwhelming. Respite is a caregiver focused service that allows family members to take a much-needed break from the daily emotional and physical stresses associated with caring for a loved one at home. It also allows family caregivers to attend to financial and practical matters that occur outside their roles as caregivers, such as taking time to pay bills, go grocery shopping or go to a doctor's appointment for themselves.

There are many forms of respite care, including at-home visits by a trained professional, adult day care services or even volunteer respite services provided by local religious or civic organizations. While the demand for respite care services continues to grow at an almost exponential rate, many Americans today are confused by or unaware of the daunting array of public and private respite care options, but may also have difficulty understanding and navigating the complicated regulations and eligibility requirements for various public programs offering access to respite care.

The Lifespan Respite Care Act is an important first step that will set up clearinghouses of information to educate consumers about respite care options available in their areas. It will also allow States to offer consumer information on the broad array of programs offering long- and short-term care support services. The legislation also provides funding to build the needed infrastructure and coordinating capacity at the State and local levels so that more people will have access to respite care, especially those in rural and underserved parts of the country.

For example, this is especially important for people living in many areas of my congressional district in northern Georgia, where people must often drive long distances to access the nearest doctor, hospital or long-term care facility. The bill will also support family caregivers in their noble and compassionate efforts to keep their loved ones at home. Numerous studies have shown that at-home care by a loved one can delay or prevent placement in expensive long-term care facilities, such as a nursing home.

Because the Federal Medicaid program is the primary purchaser of nursing home care in the United States, this informal at-home care saves the Federal taxpayers millions of dollars a year. Other studies have verified what most of us already know. People are healthier and happier when they can live at home. The availability of respite care plays an important role in enabling family caregivers to keep their loved ones at home and delays or avoids other much more expensive options.

This legislation is only a first step in addressing the emerging needs of family caregivers in the United States. To solve this problem, we will need government, health insurance companies, long-term care and other health care providers and consumers all working together to find innovative solutions.

At this time, I would like to acknowledge the efforts of my colleague and vice-chairman of the Subcommittee on Health, the gentleman from New Jersey (Mr. FERGUSON). His passion on this issue is truly commendable, as are his tireless efforts to address so many health care concerns of importance to the American people. I would also like to thank Randy Pate of the Subcommittee on Health staff, and Mr. David Rosenfeld, formerly of our staff, for their hard work on this important legislation.

Mr. Speaker, I would strongly urge my colleagues to support my bill.

Mr. Speaker, I reserve the balance of my time.

Mr. PALLONE. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, I rise today in support of H.R. 3248, the Lifespan Respite Care Act of 2006, and I am glad to be a cosponsor of this legislation. Respite care programs are an integral part of the long-term delivery systems for long-term care. All too often family caregivers provide arduous and ongoing care for aging and disabled loved ones. The programs contained within this legislation seek to provide interim relief in these situations and for those overextended families.

Despite the numerous Federal programs that have the potential to fund respite services, there is no single coordinated caregiver friendly program to support the development or implementation of lifespan respite care services. Even where resources are available many families cannot find providers who are adequately trained to

care for people with disabilities who can provide them the temporary relief that they desperately need.

The Lifespan Respite Care Act of 2006 would authorize the award of grants and cooperative agreements to eligible State agencies to develop or enhance lifespan respite care programs at the State and local levels. These grants and cooperative agreements would provide assistance to programs that provide training, information, counseling and access to the range of publicly supported long-term care programs for family caregivers of children and adults with special needs.

State agencies would work to ensure meaningful involvement of family members, family caregivers and care recipients. This bill would also establish the National Resource Center on Lifespan Respite Care to provide technical assistance, information referral and educational programs on lifespan respite care.

Without respite and other services of support for family caregivers, many are forced to quit their jobs or reduce their paid employment. Other would-be caregivers are forced to place their relatives in unwanted and more costly institutional or foster care programs.

H.R. 3248 enjoys a great deal of bipartisan support, as well as support from a diverse stakeholder community, including Easter Seals, the National Education Association, the National Mental Health Association and the Children's Defense Fund. I would like to thank Mr. FERGUSON for sponsoring this legislation and urge my colleagues on both sides of the aisle to support this bill.

Mr. Speaker, I reserve the balance of my time.

Mr. DEAL of Georgia. Mr. Speaker, I am pleased to yield 10 minutes to the author of the legislation, the gentleman from New Jersey (Mr. FERGUSON).

Mr. FERGUSON. Mr. Speaker, I rise today in support of H.R. 3248, the Lifespan Respite Care Act. This important bipartisan legislation will for the first time establish a national policy to help our Nation's 50 million family caregivers, including 900,000 New Jersey family caregivers who provide daily care for their loved ones with disabilities and chronic conditions or illnesses.

Instead of an institutionalized setting, in-home family caregivers provide minute-by-minute special assistance to a loved one with a disability or a critical illness or a chronic condition. Mr. Speaker, family caregivers are remarkable people. They make extraordinary sacrifices to help those whom they love so dearly. I saw one such example firsthand almost 10 years ago when my mom was diagnosed with multiple myeloma. For 6 years, my dad cared for her as she battled cancer.

She lived longer than any of her doctors thought she would, and since she went to heaven 3½ years ago, our family has looked back on those extra

monuments we had with our mom, and we treasured them, knowing that it was my dad's love and care which helped to make them possible.

There are tens of millions of family caregivers in this country who provide the same loving and compassionate care that we saw my dad provide for my mom near the end of her life. In our family we were fortunate to have a support structure of relatives and friends who were able to provide a break for my dad when he really needed one. That respite was crucial for him. For him to stay healthy himself, it enabled him to provide better care for my mom.

But there are countless caregivers around this country who are not blessed with that built-in support structure, and they are desperately in need of a break from time to time. Because while the benefits of in-home care can be significant for the family, compared with institutionalized care, the cost for the family caregiver, from emotional to financial, can be enormous.

All across the country there are people like Karen Pinter of Hillsborough, New Jersey, providing in-home care. Karen provides round the clock care for her 10-year-old autistic daughter, Jessica. For Mrs. Pinter, respite means receiving \$40 once a week from the New Jersey Family Support Center so that she can hire a tutor for her daughter.

With a tutor, Karen Pinter can take a much-needed break so she can do simple things for herself and for her family that many of us take for granted, like writing out that week's grocery list or preparing dinner or paying bills or simply taking a break for herself.

Respite for Eugenia and Roger Gore of Scotch Plains, New Jersey, helps their family to make ends meet. Their family uses respite hours so their 13-year-old autistic son can attend an extended-day program at school so Mrs. Gore can work outside the home to help further support their family.

Now the Gore family uses their respite funds to enable Mrs. Gore to work outside the home. This helps alleviate a financial burden, but it does not allow their family the break that respite oftentimes would. Even as they applied to the State of New Jersey for support for some respite hours on a weekend so they could get that much-needed break for grocery shopping or to attend one of their other son's athletic games, unfortunately they were denied.

For caregivers providing intense and exhausting care 24 hours a day, 7 days a week, 365 days a year, the occasional short break can literally be a lifesaver. That is what respite care is. It is providing a break for caregivers.

Mrs. Pinter has told me that caring for a special needs child can be very joyful. It can also be very challenging, and she is right. Family caregivers suffer poor health and even higher mortality rates than non-family care-

givers, according to some recent studies. For example, mortality rates among older caregivers are 63 percent higher than among older non-caregivers. Two-thirds of family caregivers report physical or mental health problems that are linked to their care giving.

Nationally, there is no coordinated approach that exists among different levels of government or advocacy groups to help those who need respite care to find it and to qualify for it and to pay for it.

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The problem is that respite care is in short supply or it doesn't exist at all in some areas. This legislation that we are considering today would change that. The Lifespan Respite Care Act would improve coordination and access for respite care and recruit and train respite care providers. With \$289 million over the next 5 years, the bill would also aid family caregivers in finding and paying for respite services through competitive grants to States to make quality respite care available and accessible, regardless of age or disability or family situation.

National and grassroots advocacy groups, including the AARP, Alzheimer's Association, Epilepsy Foundation, National Multiple Sclerosis Society, Paralyzed Veterans of America, The Arc of the United States, and United Cerebral Palsy, they all support this legislation.

Why does this legislative effort have such strong support from such reputable organizations and many others? Because we know respite care works. Respite care improves the health and well-being of caregivers and reduces the risk of abuse or neglect. Importantly, it also delays or even avoids more costly hospitalizations or placements in nursing homes or foster care.

Mr. Speaker, for over 2 years I have been working tirelessly with many of our colleagues on the Energy and Commerce Committee on both sides of the aisle to bring this bill to the floor. I want to thank Chairman BARTON for his support and the ranking member of our committee, Mr. DINGELL. I want to offer a special word of thanks to Chairman NATHAN DEAL for his support of this bill. I know his heart is very close to this effort. I want to thank the ranking member, Mr. PALLONE, as well for his strong support of this legislation.

I also want to thank the over 180 national and State and local organizations who, under the direction of the National Respite Coalition and its chair, Jill Kagan, who is here in our Chamber today with us, we have worked tirelessly on behalf of the Nation's family caregivers on this issue. I want to thank Tom Fussaro from our staff in our office, and Eric Joyce from the Family Resource Network and the Epilepsy Foundation of New Jersey. And I particularly want to thank Mr. LANGEVIN, the gentleman from Rhode

Island, who has been such a strong supporter and my partner in this legislation all along the way.

Finally, I want to thank my dad, who has provided our family and many others with a remarkable example of the loving care that a family caregiver can provide.

Providing relief to our Nation's family caregivers is long overdue, and I urge my colleagues to support this legislation. Today's action by this House will represent not only an important victory for family caregivers nationwide but also sends America's caregivers a very clear message: Your selfless sacrifice is appreciated, and help is on the way.

Mr. PALLONE. Mr. Speaker, I yield 4 minutes to the gentleman from Rhode Island (Mr. LANGEVIN).

Mr. LANGEVIN. Mr. Speaker, I thank the gentleman for yielding.

Mr. Speaker, I want to thank the gentleman from New Jersey (Mr. FERGUSON), my partner in this effort, for his leadership on this exceptional bill.

Mr. Speaker, it is with great enthusiasm that I voice my strong support for the Lifespan Respite Care Act. For more than 4 years, I have worked to pass a bill that would ease the burden of responsibility on family caregivers.

I particularly want to acknowledge the hard work of so many advocates, organizations and individuals who worked with me to get this bill to where it is today. In particular I want to thank the chairman of the subcommittee, and I also want to thank Jill Kagan of the National Respite Coalition for her tireless efforts over many, many years.

Mr. Speaker, an estimated 26 million Americans are currently caring for an adult family member who is chronically ill or disabled. Additionally, an estimated 18 million children have chronic physical, developmental, behavioral or emotional conditions that place significant demands on their parents. Family caregivers live in all of our communities and they are often silent heroes, ensuring family stability and helping those who struggle with disease or disability to avoid more costly institutional placements.

While voluntary care is personally rewarding, it can result in substantial emotional, physical and financial strain on the caregiver. When one family member is caring for another, it doesn't mean that the other responsibilities of the family simply stop. Children still need to be brought to school, food shopping still needs to be done, doctors appointments still need to be made and kept, particularly when it involves the caregiver themselves.

Mr. Speaker, they need to know that they are not alone and they need to know where to turn when the pressures of their situation become too much for them to bear. Respite care services relieve caregivers from daily care giving tasks on a temporary or even long-term basis.

Many lifespan respite programs are already in place at State and local lev-

els, providing invaluable services to the families of people with chronic disease or disability. Yet in too many situations, caregivers simply don't know how to find information about available respite care and access to these services. In other cases, respite care is simply unavailable to those who need it.

I originally introduced the Lifespan Respite Care Act in the 107th Congress, working with the National Respite Coalition to craft a bill that would assist States and local organizations in identifying and filling the gaps in their systems. While I do wish we could have addressed this important issue sooner, I am grateful to Representative FERGUSON for his leadership in ensuring that this bill came to the House floor. By passing this legislation and committing to build upon successful existing programs, we can make a powerful statement to so many Americans who are silently struggling right now. It is a statement of gratitude for their many hours of work and a statement of support for when the challenges become too daunting.

Mr. Speaker, I thank the congressional leadership for their hard work in moving this bill forward and bringing it to the floor today, and I urge all of my colleagues to vote in favor of the Lifespan Respite Care Act. To the people at home, help is on the way.

Mr. FERGUSON. Mr. Speaker, today I rise in support of H.R. 3248, the Lifespan Respite Care Act. For over 2 years I have been working diligently with many of my colleagues on the Energy and Commerce Committee to bring this bill to the floor. Over 180 national, State and local organizations under the direction of the National Respite Coalition have worked tirelessly on behalf of the Nation's family caregivers to help us get to this point. This legislation will for the first time establish respite as a policy priority for the Nation's estimated 50 million family caregivers, who daily provide care for their loved ones with disabling or chronic conditions or illnesses.

Most caregivers freely and willingly provide this care out of love and commitment, but often at great cost to themselves physically, emotionally, and financially. One in five caregivers report that they are in fair or poor health; 43 percent report having a chronic health condition that requires ongoing medical care, putting themselves at great risk and jeopardizing their ability to provide continued care to their dependent loved ones. An estimated 46 percent to 59 percent of family caregivers are clinically depressed. A recent medical study found that older caregivers who were providing care for an elderly individual with a disability and experiencing caregiver strain had mortality rates that were 63 percent higher than non-caregiving controls.

Caregivers are stretched thin in others ways as well, often with lost income and multiple family responsibilities. Nearly half of caregivers—48 percent—providing care to child, adult or elderly family members who have chronic or disabling conditions, have other children under age 18. Forty-two percent have family incomes below 200 percent of poverty compared to 34 percent of women without family caregiving responsibilities. While most

caregivers are employed, many are forced to make extreme financial sacrifices in order to continue to provide care. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care interfered with parents accepting job opportunities. Over the course of a caregiving "career," family caregivers providing intense personal care can lose as much as \$659,000 in wages, pensions and Social Security.

The cost to U.S. businesses is even more staggering. A new study by Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions.

Still, many barriers exist to accessing respite—including a reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even when respite is an allowable funded service and resources are available to pay, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for. A New Jersey mother of a 12 year old with autism was denied additional respite because she was not a single mother, was not at poverty level, and was not exhibiting any emotional or physical conditions herself. As she told us, "Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service."

Respite, the most frequently requested service among family caregivers, offers a temporary break from the rigors of continuous care and helps sustain their own health and well-being. Others are able to tend to an emergency situation or personal health crisis. For a caregiver providing intense and exhausting care 24 hours a day, 7 days a week, 365 days a year, an occasional short break can literally be a life saver.

Respite reduces stress, enhances caregiver health and well-being, and ensures the safety and health of the loved ones in our care. Studies have shown that respite care for family caregivers has resulted in fewer hospitalizations for the children and elderly family members in care. Respite has also been shown to help reduce the likelihood of abuse and neglect and foster care placements. Research conducted by the ARCH National Respite Resource Center has also shown that respite can help keep marriages intact and enhance family stability. Another study found that if respite care delays institutionalization of a person with Alzheimer's disease by as little as a month, \$1.12 billion is saved annually.

The bill authorizes \$289 million over 5 years for competitive grants to States through Aging and Disability Resource Centers working in collaboration with State respite coalitions or other State organizations. These organizations provide or have expertise in respite to make

respite available and accessible to family caregivers, regardless of age or disability, through coordinated lifespan respite systems. This legislation would help States maximize the use of existing resources and leverage new dollars by building on current services and systems that States already have in place. The bill would help support planned and emergency respite, respite workers and volunteer training and recruitment, caregiver training, and program evaluation.

The congressional intent of the legislation is to ensure that respite becomes more accessible to all family caregivers in need, especially to those who currently do not qualify for any respite programs, who have no respite programs or providers in their areas, and those who do not know where to turn to find information on how to find and pay for respite. By using the broad term child or adult with special needs, Congress intended for the State to be highly inclusive and ensure that family caregivers of children and adults with developmental disabilities, cognitive, neurological, physical and mental health conditions and illnesses be equitably served. The focus for direct service delivery should be on those who currently may not qualify for respite under any State or Federal program or who have no service available, such as individuals under age 60 with multiple sclerosis, cancer, ALS, traumatic brain injury, and spinal cord injury, or children, adolescents or adults with behavioral, emotional or mental health conditions.

Just as importantly, Congress intended that States focus immediately on establishing coordinated lifespan respite systems that will serve all age groups equally. The Secretary should ensure that State agencies and ADRCs use the funds provided by this act to serve all age groups and disability categories equally and without preference. The Aging and Disability Resource Centers were established by the administration with the intention of being one-stop shops for all individuals with long-term care needs, making them logically a good place to administer lifespan respite systems, which are meant to be one-stop shops for respite services. However, many centers are still focusing on the elderly population or adults with physical disabilities and phasing in others at a later date. For the lifespan respite care effort to work most efficiently to coordinate all respite resources in the State, share and pool providers across age and disability groups, and to maximize use of current State respite resources, the ADRCs, in implementing this particular program, must start out with the goal of establishing coordinated respite systems of community-based agencies that will serve all age groups, including children.

Congress also intended lifespan respite to be coordinated at the State level. Many of the ADRCs in the States are serving only one county or region in the State. However, this legislation mandates the establishment of state lifespan respite programs, meaning that at least one ADRC in the State must function statewide, at least for the purposes of this legislation, with the assistance of a State respite coalition or other State respite agency to ensure coordination of resources at the State level, again for maximum efficiency and cost savings.

Legislative language is also clear in mandating a Federal coordinated approach. It directs the Secretary of Health and Human

Services in implanting the program to have all agencies in HHS with respite programs or resources work collaboratively at every level, from developing program guidance and awarding grants and cooperative agreements, to monitoring and evaluation. Congress intends the following agencies to work together: the Administration on Aging, the Administration on Developmental Disabilities, the Substance Abuse and Mental Health Services Administration, the Administration on Children and Families, including the Office on Child Abuse and Neglect, Centers for Disease Control's Family Caregiving Initiative, the Maternal and Child Health Bureau, and other appropriate public health agencies in the Health Resources and Services Administration.

When considering a Federal agency to take the lead in implementation of this program, the Secretary of HHS should select an agency that is not limited in scope or mission by any age or disability category, has experience in serving all populations across disability and age groups, and will ensure that the ADRC is collaborating fully and sharing joint responsibility with a private or public nonprofit State respite coalition or organization in implementing a state lifespan respite program.

Mr. Speaker, I urge my colleagues to support this legislation. With 80 percent of long-term care provided by family caregivers, too many are shouldering the responsibility alone. At a minimum, they need respite to continue serving their loved ones at home where they belong.

Mr. TERRY. Mr. Speaker, I rise in support of H.R. 3248, the Lifespan Respite Care Act. This legislation would allow States to establish Lifespan Respite Systems to improve respite access and quality for the Nation's family caregivers regardless of age or disability. I am proud to say that the legislation is modeled on the Nebraska Lifespan Respite program, which was championed legislatively in the State by my good friend and colleague, State Senator Dennis Byars, and has made a world of difference to families in our State. I am also proud to say that this year's national respite conference was hosted by the Lifespan Respite program and the Nebraska Respite Coalition.

With passage of the Nation's second piece of State legislation on lifespan respite in 1999, the Nebraska Health and Human Services System established the Nebraska Respite Network, a statewide system for the coordination of respite resources that serve the lifespan. Six regional entities are responsible for information and referral for families who need access to respite, recruitment of respite providers, public awareness, coordinating training opportunities for providers and consumers, quality assurance and program evaluation. The Lifespan Respite Subsidy component is available to persons of all ages across the lifespan with special needs who are not receiving respite services from any other government program.

The stress of continuous care giving can take its toll on family caregivers and is one of the greatest contributing factors to caregiver illness, marital discord that can lead to divorce, and costly out of home placements. Respite has been shown to alleviate these symptoms and even help delay or avoid foster care or nursing home placements. In Nebraska, a statewide survey of a broad array of caregivers who had been receiving respite

found that 79 percent of the respondents reported decreased stress and 58 percent reported decreased isolation. In addition, one out of four families with children under 21 reported they were less likely to place their children in out-of-home care once respite services were available.

The Nebraska program works because it is efficient and maximizes existing resources across all age groups and disabilities by developing unique partnerships with Medicaid, early intervention, area agencies on aging and other state and federal programs that provide or support respite. The regional Lifespan Respite Network Coordinator recruits respite providers for Medicaid, as well as for the Lifespan Respite Program itself. The coordinator meets with staff from HHS, Developmental Disabilities, the Early Intervention program, and others on a monthly basis in order to determine need. Respite providers are recruited and trained to fill the gaps, and providers list are shared. Most importantly, all family caregiver populations must be served equally with no preference for or limitation by age or disability.

The Nebraska Lifespan Respite Program was cited as exemplary by the National Conference of State Legislatures as a model for States to emulate in implementing community-based long term care, and highlighted by the National Governors Association for best practices. I would urge the Secretary in implementing this program to base its program guidance on the success of the Nebraska model, especially in its ability to reach out to and serve all age groups, and I urge my colleagues to join me in supporting this important legislation today.

Mr. PALLONE. Mr. Speaker, I urge my colleagues on both sides of the aisle to support this bill, and I yield back the balance of my time.

Mr. DEAL of Georgia. Mr. Speaker, I likewise would urge the adoption of this resolution, and would yield back the balance of my time.

The SPEAKER pro tempore (Mr. BASS). The question is on the motion offered by the gentleman from Georgia (Mr. DEAL) that the House suspend the rules and pass the bill, H.R. 3248, as amended.

The question was taken; and (two-thirds of those voting having responded in the affirmative) the rules were suspended and the bill, as amended, was passed.

A motion to reconsider was laid on the table.

#### AMENDING PUBLIC HEALTH SERVICE ACT TO MODIFY PROGRAM FOR SANCTUARY SYSTEM FOR SURPLUS CHIMPANZEES

Mr. DEAL of Georgia. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 5798) to amend the Public Health Service Act to modify the program for the sanctuary system for surplus chimpanzees by terminating the authority for the removal of chimpanzees from the system for research purposes.

The Clerk read as follows:

H.R. 5798

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*